St. Amant

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My name is Linda St. Amant. I have had the pleasure of taking care of my son David since his accident on May 30, 2003. Has it be difficult? You bet. I get to see him every day without having to go to a nursing home or a cemetery. David is a survivor of a diffuse, severe brain injury that involved the basal ganglia and brain stem. There was a three month coma. After two weeks in the hospital we were told to consider custodial care. The fractures would heal but the brain might not. We heard about Mary Free Bed Rehabilitation in Grand Rapids. We fought our insurance to get him there. He was there five months and continues to do therapy still.

David's brain injury left him without muscle memory, he had to relearn everything. It took two months to get his mouth open that confirmed where the tooth came from that was in his lung. Imagine having to learn your position in space, swallowing, vision (his eyes could see but didn't know how scroll or scan or use peripheral vision), body temperature regulation, bowel and bladder control, speech and walking. Purposeful movement - what's that! All this could not be done in 52 or even 104 weeks. Five years after the accident he started with C.H.U.M theraputic horse riding. There was an immediate improvement with balance and breath support (needed for speech intelligibility). Just last year David began wearable stim therapy, Axiobionics. This was a huge leap forward, nine years post accident. I suspect that HB 4612 would consider this experimental and therefore not cover it.

Recovering from TBI is a process often times having no end. HB 4612 eliminates life time care. So is David done? Without continued Botox and physical therapies he would slowly lose what he has worked so hard to gain. In regard to the convenience issue, would it be considered a convenience to have a second shower put in so the rest of the family doesn't acquire MRSA?

The language in the "most appropriate location" section, does that mean not at home? The support of family is crucial for the best outcome. Nieces and nephews growing up with an appreciation for inclusion. The proposed restrictions on attendant care are not well thought out. Limiting care rendered by a family member to 8 hours per day is unrealistic. Safety is the primary concern here. The list of dangers includes the obvious choking, falling, medication monitoring, and what about the misguided anger issues. Anger is a common issue following brain injuries. I have to sleep with a monitor. There are showers and shaving and nail cutting and body checks to make sure that little pimple isn't a raging MRSA sore.

Transportation considerations. What would be more cost effective, me driving David to his appointments or using a service? By the way, they're great, but I'm sure more expensive.

There are cost control measures already in place. I have to submit for reimbursement and since my husband passed last year I haven't had the time to do so!

There is so much more I could share with you. The world of traumatic brain injury is unique. I pray you do not have to experience it first hand, but only then will you get it. We should be proud that Michigan is uniquely positioned to help our wounded warriors. I would like to end this with my journal entry of June 11, 2003. 'Today I feel I have the strength to start this most difficult journal. It is day 12 after the accident. I

suspect that our frame of reference will be before or after the accident." Boy, was I right. On day 14 I wrote, "I need to remember that night because we prayed for him to live." Today I pray that you make the right decision to offer the best quality of life.

Thank you.